

June 5, 2024

Micky Tripathi, PhD, MPP  
National Coordinator  
Office of the National Coordinator for Health Information Technology  
U.S. Department of Health and Human Services  
330 C Street, SW, 7th Floor  
Washington, DC 20024

Re: Health Equity by Design (HEBD) Concept Paper

Dear National Coordinator Tripathi:

On behalf of the physician and medical student members of the American Medical Association (AMA), I appreciate the opportunity to provide feedback on the Office of the National Coordinator for Health Information Technology's (ONC) proposed Health Equity by Design (HEBD) approach. The AMA commends ONC for its commitment to leveraging health information technology (IT) to mitigate and ideally eliminate widespread health disparities arising from systemic inequities within the U.S. health and health care systems.

The AMA strongly supports the systematic integration of health equity considerations at every phase of health IT system design, policy development, and implementation and agrees that while health IT cannot address all societal and institutional factors driving health inequities, it is crucial in identifying and mitigating health disparities and ensuring that health IT does not perpetuate or magnify existing gaps. In addition, given the highly sensitive nature of an individual's personal information, it is critical that ONC's equity initiatives support safeguards around patients' and other individuals' privacy interests and preserve the security and integrity of one's personal information. The AMA is deeply invested in ensuring that individual patient rights and protections from discrimination remain intact and that these assurances are guaranteed. Sharing this information must be based on an individual's personal preferences. Data segmentation is a critical technology for health information exchange, regardless of where the data resides, how it is used, or with whom it is exchanged.

Patient consent and privacy, data provenance, governance, and state and federal law compliance should be inherent in technology development. Individuals may request that information is withheld, but due to the lack of data segmentation capabilities, large sections of an individual's medical record or personal history are either withheld or sensitive personal health information is released without knowledge. ONC should ensure its health equity initiatives are in alignment with Department of Health and Human Services work to support safeguards around individuals' privacy interests and advance broader data segmentation capabilities.

### *Specific Actions and Tools Supporting Health Equity by Design*

The AMA is engaged in several initiatives and projects that align with the HEBD approach and supports its objectives. These examples highlight the AMA's collaborative approach that centers reparative participation of, and investment in, historically marginalized and minoritized people and communities

with content areas of focus including demographic and social driver data standards and equitable algorithms and augmented intelligence:

- [AMA External Equity & Innovation Advisory Group](#): The Advisory Group was established to help guide the AMA in delivering upon its commitment to ensure equitable opportunities and conditions in health innovation for historically marginalized and minoritized people and communities. The AMA is partnering with founding collaborator organizations to support the [In Full Health Learning & Action Community](#) with content, tools, resources and opportunities to connect, engage and learn with and from each other to advance equitable health innovation. The In Full Health initiative seeks to advance equitable opportunities in health innovation investment, solution development, and purchasing and has released initial principles around equitable health innovation.
- [Health Equity Data Collection and Standards](#): The AMA actively advocates for more equitable data standards and enhanced interoperability and supports the inclusion of social determinants of health, race, ethnicity, sexual orientation, gender identity, and disability data elements in the United States Core Data for Interoperability. These standards enable consistent data collection and better identification of health disparities. The AMA has joined with the Association of American Medical Colleges and the Accreditation Council for Graduate Medical Education to create the Physician Data Collaborative, which is examining opportunities to use physician demographic data to advance health equity. The Collaborative is also using existing data relationships to model and document the processes by which the simplification of data sharing can be accomplished, including simple data sharing agreements based upon principles to support research using demographic data.
- [Improving Interoperability and Data Exchange](#): The AMA is involved in initiatives to enhance electronic health data exchange. By promoting standardized data exchange protocols, the AMA aims to ensure that health IT systems can effectively share and use data to identify and address health inequities. The AMA was a founding member of the [Gravity Project](#), a Robert Wood Johnson-funded initiative with more than 2,500 participants from organizations and entities representing health care, social services, payers, technology vendors, and government agencies working to develop consensus-driven data standards to support the collection, use, and exchange of SDOH data.
- [Harmful Race-Based Algorithms](#): As part of broader efforts to transform health care through coordinated and collective action, the AMA and Council of Medical Specialty Societies are convening professional societies around foundational actions to advance equity, including the elimination of harmful race-based clinical algorithms and other organizational-level contributors to inequitable access to health services. The AMA has highlighted the related efforts of state medical associations and national medical specialty societies that make up the AMA Federation of Medicine in its “Health Equity in Organized Medicine” [survey report](#).
- [Equitable Augmented Intelligence](#): The AMA released [principles for augmented intelligence \(AI\)](#), often called artificial intelligence, development, deployment, and use, underscoring the organization’s commitment to supporting the implementation of national governance policies that prioritize the development and deployment of AI in a manner that is ethical, equitable, responsible, and transparent. The AMA is also among health care organizations and ecosystem partners creating and disseminating continually updated best practices for implementing AI and cultivating a community of practice through the Health AI Partnership.
- [Physician Training and Education](#): The AMA provides training and resources for physicians to better understand and address health inequities. This includes education on using health IT to

collect and analyze data on social drivers of health and demographic data, to guide implementation of focused interventions, such as [AMA STEPS Forward®](#).

- Collaboration with Community Organizations: The AMA collaborates with community organizations to leverage health IT for population-level interventions. By sharing data on structural and individual social drivers of health, these collaborations help to improve equity and reduce disparities.

*Comments and Recommendations on HEBD Aims and Activities*

The AMA supports ONC's aims to ensure that health IT systems, workflows, and policies focus on eliminating disparities and contributing to equitable health outcomes. We agree that health IT systems should be designed to identify and quantify disparities and target upstream causes to prevent avoidable downstream health conditions.

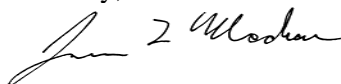
To further strengthen the HEBD approach, we recommend the following:

- Enhanced Collaboration: Commit resources to intersectoral and regional convenings that foster collaborations between federal agencies, health care providers, and community organizations to share promising practices and develop comprehensive strategies for implementing HEBD informed by those most impacted by inequities.
- Implementation Support: Provide detailed guidance, dedicated technical assistance via cooperative agreements, and infrastructure investment via grants to support implementation of HEBD principles in various health care settings, particularly small physician practices and institutions operating in rural areas and other communities that have historically experienced marginalization and disinvestment, as they face unique challenges and/or undue burdens.
- Data Integrity: Continue to engage those most impacted in updating data standards that support data sovereignty for individuals and communities, data standards that support disaggregation to faithfully represent historically marginalized communities, certification standards that move away from decision support, algorithms and AI that create, sustain, or amplify inequities, and interoperability focused on enabling low or no-cost access for entities serving historically marginalized communities and actionable in-the-moment connection to tailored and appropriate resources.
- Ongoing Evaluation: Develop mechanisms for regular evaluation involving feedback from people and communities most impacted by inequities to ensure that health IT systems remain adaptable and responsive to emerging health equity challenges.

In closing, the AMA fully supports ONC's HEBD approach and is committed to collaborating with ONC and other contributors to advance health equity through innovative health IT solutions. The AMA looks forward to contributing to this vital initiative and to ongoing discussions on how best to integrate health equity into IT design, implementation, and policy.

Thank you for the opportunity to provide feedback. If you have any questions, please do not hesitate to contact Margaret Garikes, Vice President of Federal Affairs, at [margaret.garikes@ama-assn.org](mailto:margaret.garikes@ama-assn.org).

Sincerely,



James L. Madara, MD